

## **SPINA BIFIDA**

### **CLINICAL PRACTICE GUIDELINES**

Clinical Practice Guidelines represent the minimum requirements for providing care for individuals with Spina Bifida. Care and treatment should be provided in a manner that includes adherence to and consistency with each of the following Guidelines.

#### **CRS Enrollment:**

Patients diagnosed with Spina Bifida must be seen at a site with a Spina Bifida Clinic.

#### **Interdisciplinary Team Membership:**

The following Team Members must be present during regional clinics and team conferences to review the patient information and determine the need to see the patient at a clinic site and must be available for inpatient consultation or coordination of care with inpatient staff:

- Pediatrician
- Neurosurgeon
- Orthopedist
- Urologist
- Physical Therapist
- Nutritionist
- Social Worker
- Registered Nurse Coordinator
- Occupational Therapist
- Child Psychologist
- Genetic Counselor/Nurse
- Nurse with expertise in Bowel and Bladder Care
- CRS member / Caregiver
- Primary Care Physician (Invited)<sup>1</sup>

#### **Available Personnel:**

The following personnel must be available to the member at the Spina Bifida Clinic:

- Advocate

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<sup>1</sup>The Primary Care Physician will be invited to attend all Interdisciplinary Team meetings.

- Child Life Specialist
- Orthotist
- Skin / Wound Specialist (may be RN/LPN with additional expertise in Wound Care)
- Translator
- Educator

### **Consultative Personnel:**

The Regional Clinic must have access for consultation to specialists including, but not limited to the following:

- Audiologist
- Cardiologist
- Endocrinologist
- Gastroenterologist
- Geneticist
- Nephrologist
- Pediatric Neurologist
- Ophthalmologist
- Otolaryngologist
- Plastic Surgeon
- Pulmonologist
- Psychiatrist
- Physiatrist

### **Outreach Clinics:**

Outreach Clinics are designed to provide a limited specific set of services including evaluation, monitoring and treatment in settings closer to the family than a Regional Clinic. Major treatment plan changes must be communicated to the regional clinic.

Members with spina bifida may be seen in other specialty clinics including Orthopedic, Urology, Neurosurgery and Neurology outreach clinics.

Outreach clinic records must be provided to the Regional Clinic serving the member.

**Facilities & Services:**

1. Radiology services of a quality and consistency to effectively monitor changes in spinal curve, full service neuroradiology lab and urodynamic lab availability.
2. Equipment and expertise to measure height and weight.
3. Access to the pharmacy.
4. Latex safe environment.

**Team/Staff Meetings:**

Team and staff meetings will be held based on the age of the patient and their diagnosis. At a minimum the following will occur:

1. Interdisciplinary Team Meetings: review and planning meetings (patient specific meetings) are to be held at least once a year. Based on the individual impairment, the Team may determine that once every two years is appropriate.
2. Staff meetings annually to focus on issues of clinic patient care and clinic administration.
3. Education meetings once a year to focus on new information regarding the care and treatment for persons with spina bifida. These may be off site meetings and are to be made available to staff and the CRS members and caregivers.

**Lead Physician Specialists:**

Qualifications: The Lead Physician Specialist should be a pediatrician with experience and expertise in spina bifida.

**Radiation Exposure:**

Care should be taken when ordering radiology studies to consider cumulative radiation exposure to the child. The technique that produces the best result with the least radiation exposure should be utilized.

**GUIDELINES FOR PATIENT SERVICES, EVALUATION AND MONITORING FOR SPINA BIFIDA**

The purpose of these guidelines is to promote a uniform level of care at CRS Clinics for members with spina bifida and to provide a general framework for good patient care. Their relevance to specific situations will depend on individual variations in clinical course and professional judgment. In addition, this document should serve as a tool to assess programs,

secure resources needed to enhance patient care and education, and guide the future development of treatment of spina bifida.

### **Diagnosis Treatment:**

**Goal:** To provide accurate and timely diagnosis of spinal deformities.

**Goal:** To maintain maximum functioning and monitor for signs of deterioration in motor functioning, urinary and bowel continence, central nervous system functioning and skeletal alignment.

See Guidelines for Spina Bifida Health Care Services Throughout Life; Spina Bifida Association of America, Professional Advisory Council, June 1990, or updates as available.

### **Ongoing Patient Evaluation and Monitoring:**

**Goal:** To anticipate and treat physical and psychosocial problems and management of the condition.

Make sure a social worker is available to the family.

Provide access to a nurse with experience in working with members with spina bifida.

See Guidelines for Spina Bifida Health Care Services Throughout Life; Spina Bifida Association of America, Professional Advisory Council, June 1990 for monitoring / clinic scheduling.

## **GUIDELINES FOR SELECTING SURGICAL CANDIDATES FOR DISLOCATED HIP IN CHILDREN WITH SPINA BIFIDA**

1. Selection Criteria. Unilateral hip dislocation may be considered for surgical treatment in a child of any age when associated with one or more of the following:
  - a) X-ray evidence of deterioration in scoliosis or pelvic obliquity
  - b) Documented pain
  - c) Ischial pressure sores
  - d) Documented deterioration of sitting alignment which can no longer be addressed through the child's seating system
  - e) Documented deterioration in standing or assisted ambulation
  - f) Other well-documented, compelling clinical conditions may be presented to the child's team for consideration of surgical intervention.

Each of these areas will be assessed and documented in MM and /or Ortho Clinic at least annually, for every child with spina bifida, in order to provide a longitudinal record.

2. Manual muscle testing and sensory testing are performed at regular age-appropriate intervals on all children with spina bifida, and will be performed on any candidate for hip reduction surgery prior to making a decision regarding surgery.
3. A decision regarding CRS coverage of a hip reduction surgery will require consensus of the child's MM Clinic team, including orthopedic surgeon, the family, physical therapist, nurse, social worker, and other professionals as appropriate to the individual child's case, and approval by the Medical Director.
4. Clinical and functional goals of the surgical procedure and expected outcomes must be documented prior to the procedure.

### **SPINAL DEFORMITIES**

Clinical Practice Guidelines represent the minimum requirements for providing care for individuals with scoliosis, kyphosis, and related spinal deformities. Care and treatment should be provided in a manner that includes adherence to and consistency with each of the following Guidelines.

#### **CRS Enrollment:**

Members diagnosed with scoliosis, kyphosis, or other spinal related conditions must be enrolled in a regional scoliosis clinic. Based on the recommendations of the interdisciplinary team, the patient may be seen in regional orthopedic clinics and orthopedic outreach clinics. Information from the regional or outreach orthopedic clinics must be provided to the regional spinal deformities clinic.

For members with multiple CRS diagnoses involved with multiple teams, the appropriate members of each interdisciplinary team shall review the patient status and refer to the Spinal Deformities Team when appropriate for treatment related to the spinal deformity.

#### **Team Membership:**

The following Team Members must be present during regional clinics and team conferences to review the patient information and determine the need to see the patient at a clinic site and must be available for inpatient consultation or coordination of care with inpatient staff:

- Orthopedic Surgeon with experience in treating members with spinal deformities -  
Lead Physician

- Registered Nurse Coordinator
- Nurse with experience in spinal deformities (May be the same as the Nurse coordinator)
- CRS member / Caregiver
- Primary Care Physician<sup>2</sup>

**Consultative Personnel:**

- Educator
- Geneticist
- Nutritionist
- Occupational Therapist
- Pediatric Cardiologist
- Pediatric Neurologist
- Pediatric Neurosurgeon
- Pediatric Urologist

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<sup>2</sup>The Primary Care Physician will be invited to attend all Interdisciplinary Team meetings.

- Pediatrics
- Child Psychologist
- Pulmonologist
- Radiologist
- Physical Therapists

**Outreach Clinics:**

Outreach clinics are designed to provide a limited specific set of services including evaluation, monitoring and treatment in settings closer to the family than a regional clinic. Major treatment plan changes must be communicated to the regional clinic.

Members with spinal deformities may receive monitoring services between site visits at the orthopedic outreach clinics. The outreach clinic must include an orthopedic surgeon with expertise in managing spinal deformities and an orthotist.

Outreach clinic records must be provided to the Regional Clinic serving the member.

### **Community Based Services not provided by CRS:**

Community based services means all local services including provider agencies, schools, private physician offices, hospitals, and/or any other local setting.

Members with a diagnosis of idiopathic scoliosis with a curvature of less than 15 degrees who are skeletally mature may be monitored in the community.

The following community based services may be provided from a community based setting:

- Physical Therapy
- Radiology Services
- Lab Services
- Pharmacy Services
- Occupational Therapy
- Nutrition Services
- Social Work Services

### **Special Equipment:**

Radiology services of a quality and consistency to effectively monitor changes in spinal curve.

### **Team/Staff Meetings:**

Team and staff meetings will be held based on the age of the patient and their diagnosis. At a minimum the following will occur:

1. Interdisciplinary Team Meetings: review and planning meetings (patient specific meetings) are to be held as follows:  
  
All patients with spinal deformities should attend an interdisciplinary regional spinal deformities clinic at least once every 6 months except for patients with a curve of less than 15 degrees who are skeletally mature who should attend interdisciplinary regional spinal deformities clinics at least once every two years.
2. Staff meetings annually to focus on issues of clinic patient care and clinic administration.
3. Education meetings annually to focus on new information regarding the care and treatment for persons with spinal deformities. These may be off site meetings. The following individuals should be included in the education meetings: the lead

physician, the members of the Interdisciplinary Team, and any other interested persons.

**Lead Physician Specialists:**

Qualifications: The Lead Physician Specialist should be an orthopedic surgeon with experience in the managing of pediatric spinal deformities in members.

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